CareFirst Hospice

Health care for the end of life

What is Hospice?

- Hospice is a philosophy- “When a person in end stages of an illness can no longer receive, or wants to receive, life sustaining treatment, he or she still deserves health care aimed at alleviating distressing symptoms of disease”

- Hospice is a choice- patients give informed consent and can choose what care they receive

Hospice

- Is an accepted health care specialty-all levels of professional provider can become board-certified in hospice care
- Is funded by most insurances, Medicare and Medicaid
- Exists as both for-profit and non-profit organizations
- Can be practiced in any setting- home, hospital, emergency room , nursing home. The service is brought to the patient, rather than the patient to the service.

What is the purpose of hospice?

- To provide alleviation and management of distressing symptoms of terminal illness
- To help the patient and family prepare for death
- To provide emotional support to the family and loved ones after the patient's death

Who is eligible for Hospice?

- Anyone with an end stage illness who has 6 months or less to live (as estimated by MD)
- Consideration is given to patients who have no clear cut terminal dx but who have multiple illnesses, recent unintentional weight loss, decline in functional status, or level of consciousness.

What does “End Stage” mean?

- How do we define “end stage”?
- How does this differ from “terminal illness?”
- What are some disease which we think of as “terminal”?
- What diseases do we NOT think of as “terminal”?

What does hospice offer?

- Hospice is unique in health care in that we are MANDATED to provide not only physical, but psychological AND spiritual care to patients.
- All patients get a Registered Nurse to manage their symptoms and physical needs.
- All patients get a Social Worker to assist with their emotional issues, including preparing for death, making closure, managing finances and navigating insurances
- Patients are offered Spiritual Care providers to minister to their spirit (NOT their religion!)

What else?

- Volunteer- unpaid people to assist with non physical care needs- running errands, socialization, caregiver respite
- Bereavement- 1 year of follow up to the family and caregivers of the patient to ensure adjustment to loss
- All members of the hospice team work with the patient, family, and Primary MD to deliver quality end of life care

How can hospice help?

- Establish normalcy- we help the patient and family to confront the disease, and the prospect of death on every level.
- Assess symptoms- what is bothering the patient? What is bothering the family and caregivers? What steps can they take to feel better?
- Refocus care- address “today”, making the time left to the patient be the best it can be.

Eligibility versus reality

- Patients who are eligible for hospice can have a MINIMUM of 6 months of hospice services
- Currently, the median length of stay for CareFirst hospice patients is 13 days.
- Currently, less than 30% of people with terminal illness in the CareFirst area die on hospice.

What is our healthcare population?

- Nearly 1 in 2 Americans is living with chronic disease
- 90% of seniors (approximately 36 MILLION people) have at least one chronic disease
- 77% have 2 chronic conditions
- 24% of those with chronic illness suffer from disability

Chronic Conditions: Making the case for ongoing care. FWJ-9/2004 update

Death in America

2011	1900
1. Heart Disease	1. Pneumonia
2. Cancer	2. Tuberculosis
3. Pulmonary Disease	3. Diarrhea and Enteritis
Life expectancy: 78.2yrs	Life expectancy: 47yrs
Disability: weeks to years	Disability: days to weeks

“Rainy Day Thinking”

“We suggest a move towards earlier consideration and more ‘rainy day thinking’ –bringing an umbrella just in case it rains. This instinctive, anticipatory and ‘insurance-type’ thinking relates more to meeting likely needs and planning ahead, rather than focusing on trying to predict likely timescales, and should ensure appropriate support and care can be mobilized”

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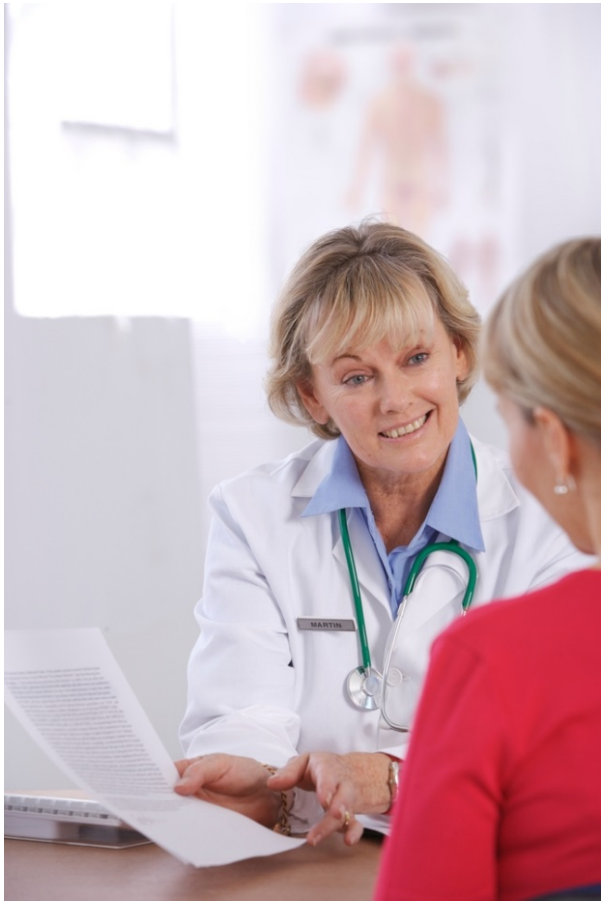
Better End of Life Discussion= Better End of Life

- Patients who had end of life discussions were less likely to receive aggressive treatment in the last four months of life
- Referred earlier to hospice
- Reported better quality of life
- Reported greater emotional comfort
- Survivors reported less depression and distress
- Aggressive TX at end of life was associated with worse patient quality of life and worse bereavement adjustment

Wright, A. A, et al. JAMA Oct 8 2008 Vol 300 No 14 (reprint)

Step 1- the “Surprise” Question

- Would you be surprised if the person died within the next year? months? weeks?
- If not, what measures might be taken now to improve the person’s quality of life and to prepare for future decline?



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Step 2- General Indicators

- Decreasing activity-decline in functional performance; Limited self care; in bed or chair 50% of time.
- Multiple diseases- the greatest predictor of morbidity and mortality
- General decline and increased need for support; increasing dependence in personal care
- Advanced disease- unstable, deteriorating, complex symptom burden
- Decreasing response to treatment- symptomatic on optimal treatment

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General Indicators (cont)

- Progressive weight loss of >10% over last six months
- Repeated unplanned hospital admissions (more than 3 in 12 months for the same disease)
- Albumin <2.5 g/l
- Sentinel event- eg fall, transfer to SNF, bereavement

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General indicators

- If a patient is declining over months, he or she probably has months left to live
- If a patient is declining over weeks, he or she probably has weeks left to live
- If a patient is declining over days, he or she probably has days left to live

CANCER

- Usually has a rapid or predictable decline
- Metastatic cancer is often an indicator of prognosis of 6 months or less
- Most important clinical indicator is performance status and functional ability - If patient is spending more than 50% of time in bed/lying down, prognosis is generally 3 months or less.

COPD

- Often has an erratic decline pattern
- Abnormal lab testing
- Recurrent hospitalizations-3 or more in last 12 months
- S/S right heart failure
- Shortness of breath with ambulation greater than 30 ft
- More than 6 weeks of systemic steroid use in last 6 months
- Recurrent upper resp. infection

CHF

- NYHA Class 3 or more- symptoms with minimal exertion
- Repeated hospitalizations
- Recurrent symptoms despite optimal medical management
- Secondary indications include an Ejection Fraction of 20% or less.

Neurological Disease

- Progressive deterioration despite optimal therapy (ie change from ambulatory to bedbound, increased personal care support needed, change to pureed diet or artificial feeding)
- Complex, poorly controlled symptoms
- Swallowing difficulty leading to aspiration pneumonia, sepsis, or respiratory failure

Dementia

- Dementia can have many underlying causes and these should be taken into account, but triggers that suggest late stage dementia are -
- 7C on the FAST scale (unable to ambulate, incontinent of bowel AND bladder, able to speak fewer than 5-6 words in a day) (FAST is a scale which measures progressive dementia based on loss of physical and mental abilities)

AND

- Aspiration pneumonia
- Wt loss of 10% in last 6 months
- Urosepsis
- Recurrent fever
- Stage 3-4 pressure ulcers

Barriers

- “It will scare the patient”- studies have shown that FAILING to discuss the patient’s status and options is detrimental to their emotional health
- “The patient and family want everything done”
- “I don’t know what to say”- if you aren’t comfortable asking the patient about their wishes, and telling them about their options, let CareFirst help.

How Can CareFirst Help?

- Facilitate open discussion with patient and family
- Educate providers on options for care
- Educate the public about the need for and scope of hospice care

CareFirst Provides…

- **Palliative Care**
- **Hospice**
- **Grief Services**

Hospice

"**CareFirst gives me the power** to take control of my illness. This is my disease, this is my story." – Hospice Patient, age 44

CareFirst Hospice Services:

- 24 hour on-call system
- Medical equipment and medications
- Specially trained nurses
- Social workers
- Spiritual care counselors
- LPN's to assist with personal care
- Professional volunteers

Palliative Care

CareFirst Palliative Care Programs:

- **Thrive**
- **Pediatric Palliative Care**
- **Perinatal Palliative Care**
- **Hospital-Based Palliative Care**

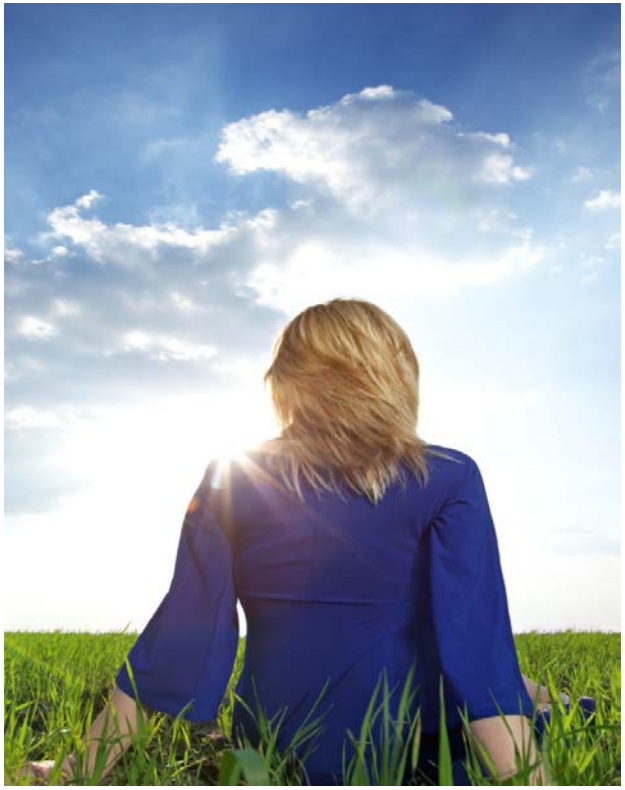
Our staff will help you navigate life with a serious illness, as well as offer caregiver education and support for loved ones

"**You think you can deal with everything yourself but you can't**. CareFirst steps in when everyone else is stepping away."
– Family Member

Grief Services

CareFirst Grief Services:

- Age appropriate grief support for children
- Individual and group counseling
- Support groups
- Memorial services
- Education and outreach
- Free of charge
- Open to all members of the community



"When I lost my husband, **CareFirst was the only place I felt understood** or heard for a very long time." – Grief Services Client

Final thoughts

- "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die." Dame Cecily Saunders, founder of modern hospice.